Global bioethics: did the universal declaration on bioethics and human rights miss the boat?

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This paper explores the evolution of the Universal Declaration on Bioethics and Human Rights (UDBHR), which was adopted by the United Nations Educational, Scientific and Cultural Organization (Unesco) in 2005. While the draft UDBHR generated controversy among bioethicists, the process through which it evolved excluded mainstream bioethicists. The absence of peer review affects the declaration's content and significance. This paper critically analyses its content, commenting on the failure to acknowledge socioeconomic and other factors that impede its implementation. The UDBHR outlines ideal standards but fails to provide guidance that can be readily applied in different settings. It strives for universality but does not contribute to understanding of universal or global bioethics.

The Universal Declaration on Bioethics and Human Rights (UDBHR) was developed through multinational consultation over several years. It was officially adopted by the United Nations Educational, Scientific and Cultural Organization (Unesco) in October 2005.[1] This paper explores the process of drafting the UDBHR, critically analyses its content and considers its status in the context of global bioethics. It comments on the UDBHR's failure to acknowledge or respond to socioeconomic and other factors that impede attempts to implement it. The paper concludes that the process of drafting the declaration excluded a necessary group of stakeholders and that the UDBHR therefore fails to provide the guidance it aims to offer.

Identifying a need to develop universally applicable ethical guidelines within a context of cultural pluralism, Unesco began developing a draft Declaration on Universal Norms on Bioethics. A near final draft was posted on Unesco's website in February 2005 and replaced in June 2005 with the version subsequently adopted as the UDBHR. Stakeholder consultation on the draft involved hundreds of people in many diverse nations. These were seemingly limited to consultations with Unesco affiliates, however, and public comment was not solicited. The consultations sought during the evolution of the declaration are chronicled on-line,[2] but from Unesco's homepage, even the UDBHR is difficult to find.

Although drafts were posted on-line, there was no transparency about disagreements that presumably arose regarding their development or evolving content. Had the process been less exclusive and more transparent and had it addressed concerns raised by bioethicists outside of Unesco, the UDBHR's claim to universality would be stronger and its impact would be more substantial. The UDBHR offers no mechanism of prioritising among competing principles,[3] restates existing goals without specifying how these can be achieved,[4] and may contribute to ''declaration-overload''.[5]

PROBLEMS WITH THE PROCESS

The process of drafting the UDBHR began in 2001, when Unesco's director-general asked the International Bioethics Committee (IBC) to draft a report on the possibility of elaborating universal norms on bioethics.[6] IBC's webpage (accessed through Unesco's Social and Human Sciences and Ethics webpages) describes IBC as ''a body of 36 independent experts that follows progress in the life sciences and its applications in order to ensure respect for human dignity and freedom''. The IBC was established in 1993, and its members are appointed to 4-year terms by the director-general. The International Association for Bioethics and the editorial boards of several international bioethics journals would surely disagree with the claim on IBC's webpage that it is the ''only global forum for in-depth bioethical reflection by exposing the issues at stake''. The IBC cannot justify its approach to the drafting process on these grounds, because this claim is inaccurate. Unesco's claim to have a leading role in international bioethics is also inaccurate, evidenced by the lack of attention to its work in peer-reviewed journals.[7]

Agreeing in 2003 that it was ''desirable to set universal standards in the field of bioethics with due regard for human dignity and human rights and freedoms, in the spirit of cultural pluralism inherent in bioethics'', Unesco asked the IBC to develop a draft declaration. In January 2004, the IBC began consulting its 190 member states through a questionnaire about desirable aims and scope of the proposed declaration. By June, 67 questionnaires had been returned, including 46 from outside the USA and Europe. Neither questionnaire nor data are available on the website, although these might contribute significantly to the bioethics literature regarding global and universal bioethics.

Sixty-six per cent of respondents to the questionnaire wanted the scope of the declaration to encompass all life forms, not just human life. At an IBC session in April 2004, consensus on this was attained by over 200 participants from 70 countries, including representatives from the World Medical Association, 15 national bioethics committees and the International Association of Bioethics. Given the widespread focus today on environmental concerns and global warming, it is not surprising that consensus was obtained on that broad point. Consensus-building offers an inclusive way forward when attempting to identify universals,[8] but it is easily obtained if principles or guidelines are worded vaguely enough to be interpreted to everyone's satisfaction.[5]

The IBC sought consensus about the draft among leaders representing mainstream views within the six largest religions (Buddhism, Roman Catholicism, Confucianism, Hinduism, Judaism, Islam). During this attempt to engage a relevant group of stakeholders, consensus about the interdependence of all life forms and the need to respect cultural and religious diversity was reinforced.[9] However, given the generality of these issues and the diverse and complex interpretations regarding values *within* a given culture,[10] the views of these spiritual

leaders do not reflect consensus on significant concrete issues.

That the UDBHR does not address the moral status of embryos and stem cells, the permissibility of their use in research or their potential contribution to improving or harming human health reflects the lack of consensus among and within religions and Unesco about controversial issues and how to address them. Some religious consultants suggested that the UDBHR offer mechanisms to enable diverse societies to seek solutions in keeping with their own moral traditions and to balance competing values in a multicultural context. The UDBHR does not do so, however, either because no consensus emerged on these important points or because no one was able to identify or incorporate such mechanisms.

Unlike the Nuffield Council on Bioethics and others that have elicited public comments regarding draft documents, the IBC was seemingly oblivious to even published comments about the final draft. (Ten papers and an editorial about the draft UDBHR were published in a special issue of *Developing World Bioethics* (2005, **5**:iii–279.) Given Unesco's stature and resources, it should have established channels for public comment, anticipated divergent views among bioethicists and engaged the bioethics community in drafting the declaration. It should have taken more seriously the implications of creating a ''universal'' declaration, particularly one addressing bioethics. This might have resulted in a UDBHR that expanded upon, rather than reiterated, existing documents on research ethics and offered realistic guidance showing that its authors were cognizant of socioeconomic and other inequities. Given Unesco's understanding of cultural diversity and human rights, it should also have engaged marginalised populations, in addition to the appointees representing them.

Some wonder whether the extensive resources allocated to developing the UDBHR were wasted.[5 7] These might have been better used to conduct and publish research upon which to ground a universal declaration of bioethics. Without solid evidence that its ideals are universal and possible to implement, the UDBHR lacks academic rigor and credibility in the bioethics community and will have limited impact. Capacity-building efforts (and declarations) must be responsive to the cultural and socioeconomic realities of diverse stakeholders and may take years to bear fruit.[11]

Stakeholder perceptions determine the final usefulness of declarations and development efforts, so stakeholder consultation should not be rushed. Unesco anticipated the need for international bioethics guidance, but perhaps impatience contributed to its inability to consult effectively. The complexity of the UDBHR's aims make it unlikely that it will please everyone. It can be built upon, however, if we identify, and learn from, both its weaknesses and its strengths (which include ideal standards outlined by a prestigious organisation).

The UDBHR's claim to universality is undermined by the exclusivity of the consultation process and the lack of evidence that the UDBHR's ideals are accepted by poor or marginalised people in any nation. Its content does not address the cultural, socioeconomic and gender-based realities that impede its implementation.[12 13] There is a complex interplay between culture, socioeconomics, justice and human development (interactions that are described in detail by London[14] and Farmer and Campos[15]) that bears on obtaining consensus and on whether values such as those expressed in the UDBHR routinely influence decisions and actions. The writers of the UDBHR do not seem cognizant of this.

PROBLEMS WITH THE CONTENT

To paraphrase articles 1 and 2, the UDBHR aims to guide state, corporate and individual decisions regarding the application of medicine, life sciences and social sciences to individuals and groups. Its numerous aims include providing a universal framework of principles and procedures to guide states in forming bioethics-related policy, promoting human dignity in bioethical issues in accordance with international human rights law and fostering multidisciplinary dialogue among pluralistic groups. The UDBHR has been criticised, however, regarding its treatment of issues including consent,[4] respect for pluralism,[13] privacy and confidentiality,[16] and non-discrimination.[7]

Rawlinson and Donchin (p260)[12] point out that issues of poverty, access to care, education and sustainable environmental resources bear on health and bioethics. They explain that universal principles cannot be articulated without recognising the implication of concepts of persons, rights and cultural and gender-based identities. They argue that the UDBHR fails to ''articulate a sense of universality ample enough to address the actual inequalities of power and resources that prevail across the globe.'' They suggest that the social responsibilities listed in article 14 (such as advancing access to quality healthcare) should be integrated throughout the UDBHR to emphasise the impact of structural inequalities on health and the necessity of social transformations and redistributions of power in addressing them.

The inability of the UDBHR to offer practical guidance derives from its failure to address the realities in which such inequalities are grounded. Article 14 requires that scientific and technological progress contribute to the common good. It does not, however, acknowledge the implications of the fact that some research is profit driven.[17] This omission renders the UDBHR unable to encourage innovative means of overcoming socioeconomic barriers to access to care. Similarly, Article 15 states that research benefits should be shared but neglects to address the unique duties of profit-driven sponsors or the challenges to identifying or sharing benefits in resource-poor nations. Inherent in such challenges is the need to distinguish between basic and secondary goods, and between guaranteed and potential benefits.[18]

The UDBHR's failure to address socioeconomic realities is also apparent in Article 18, which says that honesty, integrity and transparency should be promoted, as should ''informed pluralistic public debate, seeking the expression of all relevant opinions''. Because socioeconomic, cultural and gender-based factors impinge upon such characteristics, transparency is not the norm in many settings. In some settings, using resources to promote transparency or public debate would divert them from national priorities, including healthcare. Given Unesco's unsuccessful effort at generating or responding to public debate about the UDBHR, is it justified in demanding that resource-poor states do so?

Other articles neglect the impact of socioeconomic realities. Article 20 says that risks associated with medicine and related technologies should be assessed and managed but does not suggest how to determine that a risk warrants action or how actions might be funded. What guidance does it offer regarding real risks such as global warming? The UDBHR also ignores risks inherent in global development, such as dams, industrial pollution and human trafficking.[12] Article 21 addresses the need for research ethics review in host nations (explicit in the Declaration of Helsinki and other guidelines used regularly by stakeholders) but does not acknowledge that many host nations lack permanent research ethics committees that adhere to international standards regarding membership or procedures.[19] Article 25 outlines ''follow-up action by Unesco'' but avoids mention of capacity-building to overcome inequalities involving socioeconomics, culture, politics or gender and implement the UDBHR.

Whether or not the UDBHR's ideals are universal, the attention they have

received is minimal in most nations and cultures. Many less-developed nations lack resources with which to provide chemotherapy or pain relief for cancer patients.[11] Many national budgets are too small to provide routine prenatal care or treat HIV, malaria or disfiguring and disabling diseases that can be managed at very low cost, such as lymphatic filariasis. Should such nations divert resources to discuss, or attempt to implement, the UDBHR?

The UDBHR's use of abstract language obscures important considerations. For example, it is not clear whether "respect the life of human beings" expresses concern about torture or capital punishment, or reflects intervention by the anti-abortion movement.[16] A less controversial example is ethics committees. Article 19 could encourage standardisation of terminology and roles for ethics committees. Instead, it urges their establishment to assess research using human subjects, advise on ethical problems in clinical settings, make recommendations regarding technological developments and foster bioethics debate and education. Ethics committees of varied names are already charged with some or all of these duties. Even in wealthy nations, however, such committees lack the resources with which to fulfil all of these duties. Committees to foster debate regarding national bioethics policy and underlying concerns should be encouraged, but they need a name that distinguishes them from other ethics committees.

GLOBAL BIOETHICS AND THE UDBHR

Global bioethics is "the attempt to agree on fundamental conditions for human flourishing and to secure them for all … [I]t is a task that can not be achieved by one generation" (p412).[20] Unesco seems not to have recognised either that its attempt to establish the UDBHR was a form of global bioethics or how challenging the task would be. Challenges facing global bioethics parallel those that faced the development of the UDBHR. These include overcoming global inequities that are almost impossible to remedy, cultural differences in moral perspectives, difficulties in distinguishing moral perspectives from social customs, and lack of a global decision-making body with enforcement authority (without which any declaration's goals might remain unfulfilled).[20] The UDBHR did not overcome these challenges. Doing so requires resources and plans grounded in academic expertise and peer review, and responsiveness to the unique circumstances and contexts of host populations.

The UDBHR is neither an educational document nor a strong legal document to guide ethical deliberation within states.[4] It demands actions that many states are unable to meet, misses opportunities to offer practical guidance in different cultures and socioeconomic contexts and uses abstract language. Because it did not seek or respond to peer review, the credibility and universality of the declaration are limited.

The UDBHR has stature as a universal declaration from a prestigious organisation. Some argue that declarations promoting ideals to which people and governments ought to aspire should not offer specific guidance. The value of such declarations and guidelines, however, lies in the number of people, governments or organisations that aspire to the ideals therein. The UDBHR outlines standards for decision-making at the intersection of bioethics, national policies and globalisation. These standards have value in much of the world, but the ability to implement them is severely limited by culture, gender, politics and socioeconomic context.

The UDBHR avoids mention of cultural and socioeconomic realities that impede or preclude its implementation in many settings. It offers no innovative or practical guidance and has received little attention, and few are likely to aspire to its ideals. In the light of concerns presented here, the issues for Unesco are to learn something practical from the process of establishing the UDBHR and to identify what it can realistically do to promote the ideals of the declaration in resource-poor settings. Of particular interest might be how to promote ethical values and human rights among those driven by profit or power in both wealthy and resource-poor nations.

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